



Abstract

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Project Title: ADVANCED STAGE CHRONIC DISEASE: SYMPTOMS,
DISTRESS, CARE

Abstract: *Congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) are among the top four leading causes of death in persons age 65 and over, afflict 4.6 million and 16 million Americans respectively, and result in almost 25 billion dollars in annual health care expenditures combined. These patients can be thought of as "actively dying" as they experience a slow decline with periodic crises. The experience of both the illness and the actual dying process for the patient and family are highly complex and distinct from other illnesses. Given this, it is remarkable that the complex symptom profiles and associated distress of each disease have received less attention than those associated with cancer and AIDS. The Aims of this study are to: 1) investigate the prevalence and multidimensional nature of all symptoms experienced by patients with advanced stages of CHF and COPD; 2) determine how symptoms and outcomes change with progression of disease; 3) investigate the effect of various symptoms on the distress and quality of life of both patient and family caregiver; 4) investigate the utilization of care, including self-care and complementary medicine in addition to allopathic treatment, and 5) estimate the costs of care. Patients with advanced stage CHF (n=100) and COPD (n=100) will be recruited from Beth Israel Medical Center in New York and the Massachusetts General Hospital in Boston. Patients and their primary family caregivers will be interviewed every three months for up to 30 months. Study results can be used to enhance palliative care, contribute to provider education regarding end-of-life care, and develop education and support services for patients and family caregivers. Finally, the study will provide data on the amount, source, and costs of care that will improve planning and coordination of end-of-life care.*

Thesaurus Terms:

caregiver, chronic disease /disorder, chronic obstructive pulmonary disease, congestive heart failure, functional ability, nursing care, quality of life, terminal patient care alternative medicine, family structure /dynamics, health care cost /financing, health care personnel education, health care service utilization, human old age (65+), psychological aspect of aging, stress behavioral /social science research tag, clinical research, health services research tag, human subject

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